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Self-Advocacy and Care Transition Readiness Among Adolescents With Chronic and End-Stage Kidney Diseases

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Abstract: Background: Assessing self-advocacy and transition readiness is an integral part of any transition plan for adolescents with chronic conditions to ensure a successful transition to adult healthcare and positive health outcomes. In adolescents with chronic and end-stage kidney diseases, this assessment is of exceptional importance because of the complexity of the treatment and care process. **Purpose:** To assess self-advocacy skills and care transition readiness among adolescents with chronic and end-stage kidney diseases. **Design**: A descriptive study was conducted on 105 adolescents with chronic and end-stage kidney diseases at the hemodialysis unit and nephrology outpatient clinic in the pediatric university hospital (Zagazig University Hospitals). **Instruments**; An interview questionnaire, the patient self-advocacy scale, and the transition readiness assessment questionnaire. **Results:** It was found that more than two-thirds of the studied adolescents with chronic and end-stage kidney diseases had low total self-advocacy skills and nearly three-fifths of them had low readiness for transition from pediatric to adult health care. A highly statistically significant positive correlation was found between total self-advocacy skills and total transition readiness of the studied adolescents. **Conclusions**: Adolescents with chronic and end-stage kidney diseases had low self-advocacy skills and low readiness for transition from pediatric to adult healthcare. Moreover, self-advocacy skills and transition readiness were positively correlated. **Recommendations**: Comprehensive transition programs with structured transition planning, transition education, support, family involvement, and regular assessments to evaluate readiness and adjust the plan as needed should be implemented.

Keywords: *Adolescents, Chronic kidney diseases, End-stage kidney diseases, Self-advocacy, Transition readiness.*

Introduction

Adolescents with chronic kidney disease (CKD) or end-stage kidney disease (ESKD) face distinct medical, dental, psychosocial, neurocognitive, and intellectual challenges. The causes of CKD in adolescents are more varied than in older adults, necessitating close interdisciplinary collaboration to optimize their care (Diaz-Gonzalez de Ferris et al., 2021). Advances in technology and improved medical management have led to increased survival rates of adolescents with renal disease to 85-90%. This has led to a significant rise in the number of adolescents with childhood-onset CKD transitioning to adult care settings (Kinch et al., 2023; Riar et al., 2023).The process of transitioning from pediatric to adult healthcare begins in childhood and finishes when the patient is completely incorporated into the adult healthcare system (Marks, 2022). Transitional care is a deliberate and organized process designed to meet the medical, psychosocial, and educational or vocational needs of adolescents and young adults with chronic physical and medical conditions as they shift from pediatric to adult healthcare systems (Blum et al., 1993).

The transition from pediatric care to ongoing care must be comprehensive, developmentally suitable, and well-coordinated, necessitating extensive patient education. The aim is to ensure a seamless continuum of care for chronically ill adolescents, addressing their social and emotional growth as well as the development of independent living skills. The transition process involves four key groups: the patient, their family, the pediatrician, and the adult caregiver. Throughout this process, various challenges can arise that may complicate the transition (Fernandes et al., 2014).The transition process can involve numerous changes and challenges for adolescents with chronic conditions, making it a particularly vulnerable time, especially for those with chronic kidney disease (CKD) due to the complexity of their care (Punjwani et al., 2024). This transition is often linked to a decline in both physical and psychosocial health outcomes. Adolescents with CKD and ESKD need to develop the skills to independently manage both the medical and psychosocial aspects of their condition to ensure a successful transition (Kinch et al., 2023).

The fundamental difference between pediatric and adult care is that pediatric care is family-centered care that requires parental involvement in the decision-making process, whereas adult care is patient-centered, emphasizing autonomous and independent decision-making (Castillo & Kistos, 2017). Here comes the role of self-advocacy as a crucial factor in the transition process. Self-advocacy refers to a patient's readiness to make decisions, negotiate with healthcare providers, manage their treatment, and take proactive steps in their own best interest, such as seeking second opinions or collaborating with providers to identify the most effective treatments (Curtin et al., 2008).Self-advocacy and care transition are

closely related as care transition is a structured process designed to prepare adolescents for and integrate them into adult-focused health care. The aim is to educate, empower, and foster autonomy and independence in young patients, enabling them to manage their healthcare needs and effectively navigate the healthcare system. In the same vein, self-advocacy empowers patients to engage with physicians with greater confidence, adaptability, and reduced uncertainty (Brashers & Klingle, 1992). Patients who actively practice self-advocacy tend to seek out health information and often report higher satisfaction with their healthcare providers and the overall healthcare experience (O'Connell, Young, & Twigg, 1999; Adams & Drake, 2006).

Self-advocacy can enhance a patient's ability to seek out, assess, and utilize information to promote health (Schmidt et al., 2020). Effective self-advocacy can enhance patient-centered care, improve quality of life, lessen the burden of symptoms, and increase the use of preventive health services. Moreover, it can strengthen patients' confidence in their ability to influence their care, empowering them to address other challenges and potentially lessening inequalities and discrepancies in the healthcare system (Thomas et al., 2021). An inadequate transit ion poses a risk of poor treatment adherence and negative health outcomes (Riar et al., 2023). Maintaining continuity of care is essential for a smooth and successful transition from pediatric to adult healthcare (Punjwani et al., 2024). For adolescents with CKD and ESKD, self-advocacy, self-monitoring, and medication adherence are critical aspects of self-management. Preparation for healthcare transition can be directed toward these areas (Ferris et al., 2015). Ongoing assessment and monitoring of transition readiness is a key aspect of the transition process, as it helps identify gaps and enables the transition plan to be customized to meet each individual's specific needs (Marchak et al., 2015).

Significance of the study

Developments in chronic kidney disease (CKD) management have resulted in more adolescents transitioning to adult healthcare. However, inadequate transitions can lead to significant risks of morbidity and mortality (Varty et al., 2020). This transition is particularly challenging for adolescents with CKD due to the complex, multisystemic nature of their condition (Quaglia et al., 2014). Successful transitioning requires collaboration among adolescents with CKD/ESKD, their families, and their multidisciplinary team of clinicians in both pediatric and adult healthcare settings. During this process, adolescents with CKD/ESKD must have the opportunity to develop skills to effectively self-manage and advocate for their health (Betz et al., 2014). Poor transitional or self-advocacy skills among these adolescents reduce their chances of achieving favorable health outcomes (Zhong et al., 2020). It is important to examine self-advocacy and transition

from pediatric to adult health care to improve outcomes in these patients. So, the present study aims to assess self-advocacy skills and care transition readiness among adolescents with chronic and end-stage kidney diseases.

Purpose:

The purpose of the present study was to assess self-advocacy skills and care transition readiness among adolescents with chronic and end-stage kidney diseases.

Research questions:

1) What is the level of self-advocacy skills among adolescents with chronic and end-stage kidney diseases?
2) What is the level of transition readiness from pediatric to adult health care among adolescents with chronic and end-stage kidney diseases?
3) Is there a relationship between the level of self-advocacy skills and the adolescents' readiness for transition from pediatric to adult healthcare?

Methods

Research design:

A descriptive cross-sectional design was used in conducting the present study.

Setting:

The study was conducted at the hemodialysis unit and nephrology outpatient clinic in the pediatric university hospital (Zagazig University).

Sample:

A convenient sample of 105 adolescents with chronic (73) and end-stage (32) kidney diseases was recruited for the present study.

Sample Size:

The OpenEpi software program was used in calculating the sample size based on the findings of a study conducted to assess the transition readiness of pediatric patients with chronic kidney diseases, where 46% of the respondents did not know who would continue with their care (Močnik et al., 2022). At a confidence level of 95%, and a study power of 80%, the estimated sample size was 105 adolescents with chronic and end-stage kidney diseases.

Instruments:

Three Instruments were used in collecting necessary data for the current study as follows:

Instrument one:

An interview questionnaire that was developed by the researchers and consisted of three parts as follows:

- **Part 1:** Characteristics of the studied adolescents; This part contains demographic data, which includes, the adolescent's age, gender, educational status, and type of work (if applicable).
- **Part 2:** Medical history: This part entails medical diagnoses of the studied adolescents and the age of the disease diagnosis.
- **Part 3:** Factors related to self-advocacy and self-care practices of the studied adolescent: This part of the questionnaire is composed of 5

close-ended and 2 open-ended questions concerned with receiving illness education, source of this education, being a member or admin in patients' support groups, the ability to be a self-advocate in situations pertinent to healthcare, the ability to participate in healthcare decisions and the ability of self-care.

Instrument two: The Patient Self-Advocacy Scale (PSAS)

The 12-items Patient Self-Advocacy Scale (PSAS) that developed by Brashers et al., (1999) was used to assess the self-advocacy skills of the studied adolescents. The scale includes the following three subscales: illness education, assertiveness, and mindful non-adherence (Hermansen-Kobulnicky, 2008). The PSAS was translated and modified by the researchers to suit the study participants. The modifications included changing the disease-based focus of the original scale from "HIV or AIDS' to "chronic and end-stage kidney diseases", "US citizens" was changed to "patients" and "physician" was changed to "doctor". The modified scale was assessed for reliability and validity.

Scoring:

Responses to all items of the scale were rated on a 5-point Likert scale ranging from 1 "strongly disagree" to 5 "strongly agree" except for item no. 5 the coding was reversed. Higher scores indicate higher patients' self-advocacy skills (Ramos Salazar, 2018). The mean scores of subscales and total scale were calculated by summing scores across the items and then dividing by the number of scores. The mean scores were then changed to intervals (Pimentel, 2010) as follows;

Likert scale	Interval	Description	
1	1-1.79	Strongly disagree	Low advocacy skills
2	1.8-2.59	Disagree	
3	2.6-3.39	Not sure	Moderate advocacy skills
4	3.4-4.19	Agree	High advocacy skills
5	4-5.2	Strongly agree	

Instrument three: Transition Readiness Assessment Questionnaire (TRAQ)

The revised 20-item TRAQ 6.0 developed by Johnson et al., (2021) was used in the present study to assess the transition readiness of the studied adolescents from pediatric to adult healthcare. The questionnaire has four subscales; managing medications, keeping appointments, tracking health issues, and talking with providers (Johnson et al., 2021).

Scoring:

The questions' response options are arranged into a 5-point ordinal response scale to represent the five stages of change of the transtheoretical model from pre-contemplation to mastery (Sawicki et al., 2011). The response options include (1) "No, I do not know how", (2) "No, but I want to learn", (3) "No, but I am learning to do this", (4) "Yes, I have started doing this", and (5) "Yes, I always do this when I need to" (Wood et al., 2014). The mean scores of subscales and total scale were calculated by summing scores across the items and then dividing by the number of scores. The mean scores were then changed to intervals (Pimentel, 2010) as follows;

Likert scale	Interval	Description	
1	1-1.79	No, I do not know how	Low transition readiness
2	1.8-2.59	No, but I want to learn	
3	2.6-3.39	No, but I am learning to do this	Moderate transition readiness
4	3.4-4.19	Yes, I have started doing this	High transition readiness
5	4-5.2	Yes, I always do this when I need to	

Validity and Reliability

The validity of the study instruments was evaluated and revised by a Jury of three experts in Pediatric Nursing, Pediatrics, and Psychiatric and Mental Health Nursing. These experts reviewed the instruments for content, wording, item sequence, length, clarity of coverage, format, and overall appearance. No modifications were suggested. The internal consistency of the study instruments was assessed using Cronbach's alpha, yielding a value of 0.92 for the TRAQ and 0.75 for the PSAS.

Pilot study

A pilot study was conducted on 11 adolescents suffering from chronic and end-stage kidney diseases. This pilot was designed to assess the feasibility, clarity, and applicability of the study instruments, as well as to estimate the time required to complete them.

Ethical considerations

Ethical approval for the study was obtained from the Research Ethics Committee of the Faculty of Nursing, Zagazig University (ZU.NUR.REC #:046). Official permission to conduct the study was granted by the authorities at the pediatric hospital of Zagazig University Hospitals. Informed consent was obtained from

the participating adolescents after explaining the study's purpose and nature. Anonymity and confidentiality of the collected data were assured, and participants were informed that their involvement was voluntary, with the option to withdraw from the study at any time without any consequences.

Procedure

This study was conducted over six months, from August 2023 to January 2024. A letter was submitted from the dean of the Faculty of Nursing, Zagazig University to the director of Zagazig University hospital including the purpose and methods of data collection. Following the receiving of the necessary approvals to begin the study, the researchers collected data from the hemodialysis unit two days per week and the nephrology clinic two days/week. Interviews were conducted with the adolescents and their parents, where parents were required to sign written consent forms, and the adolescents consented verbally after having brief explanation of the study purpose and methods of data collection. The studied adolescents were asked to fill in the questionnaire sheets under the guidance of the researchers who stayed to answer any specific questions that arose while adolescents completed the questionnaire. It took the adolescent about 15 to 20 minutes to complete answering the questions.

Statistical Analysis

All data were gathered, organized, and analyzed statistically using the Statistical Package for the Social Sciences (SPSS), version 23.0 (IBM Corp., Armonk, NY, USA). Quantitative data were presented as mean ± SD and median (range), while qualitative data were presented as numbers and percentages. The Chi-square test was used to compare the percentages of categorical variables. Pearson's correlation coefficient was calculated to assess the relationships between various study variables. Multiple linear regression was used to analyze the data and explain the relationship between a single continuous dependent variable and several explanatory variables. All tests were two-tailed, with a p-value of less than 0.05 deemed statistically significant, while a p-value of 0.05 or greater was considered statistically insignificant (NS).

Results

Table 1 shows that 44.8% of the studied adolescents were within the age group of 12 to less than 14 years. Males accounted for 55.2% of the studied group. Concerning educational status, 95.2% were students, and 71% were in preparatory schools. The same table reveals that the mean age of disease onset was 7.51±3.95 years, and 40.0% presented the disease for a duration from 1-< 5 years. According to the classification of kidney disease, it was found that 69.5% of the studied adolescents were classified as chronic kidney disease, and 37.1% were

diagnosed with congenital anomalies of the kidney and urinary tract.

Table 2 shows that 61.9% of the studied sample received previous health education about their illness, and physicians were the primary source of their information at a rate of 61.9%. Only 22.9% of the studied adolescents participated in a support group for patients with the same disease, and all of them were members. Also, 50.5% of the studied adolescents considered themselves not able to advocate their rights as patients. Furthermore, 58.1% considered themselves not able to participate effectively in health decisions about the disease, and 50.5% were not capable of taking care of their health from their point of view.

Table 3 reveals that 57.2%, 61%, and 73.3% of the studied adolescents had low levels of self-advocacy skills concerning illness education, assertiveness, and mindful non-adherence domains, respectively. Overall, 67.6% of them had low total self-advocacy skills.

Table 4 clarifies that 41.9%, 52.4%, 61.9%, and 58.1% of the studied adolescents had low levels of transition readiness regarding managing medications, keeping appointments, tracking health issues, and talking with providers, respectively. Also, it was found that 57.2% of the studied adolescents had low levels of readiness for transition to adult health care.

Table 5 shows that 52.4% of the studied adolescents believe that it is highly important to manage their health care. Furthermore, 57.1% reported low scores of confidence in their abilities to manage their healthcare.

Table 6 confirms a highly statistically significant correlation between total transition readiness and total self-advocacy skills, illness education subscale, and assertiveness subscale, respectively. Additionally, self-advocacy skills were positively correlated with managing medications and talking with providers, respectively. The same table reveals that transition readiness was highly statistically significantly correlated with adolescents' self-care beliefs regarding the importance of managing their health and how confident they feel in their ability to manage their health.

Table 7 portrays a statistically significant relationship between the total score of both self-advocacy skills, transition readiness, and the abilities of the studied adolescents to advocate for their rights as patients, their abilities to participate effectively in health decision-making, and taking care of their health, respectively (p-value <0.05). In the same context, there was a significant relation between total scores of self-advocacy skills and receiving previous health education.

Table 8 presents statistically significant relationships between the self-advocacy skills of the studied adolescents and their classification of kidney disease and medical diagnosis (p-value <0.05).

Table 9 reveals statistically significant relations between the total score of transition readiness among the studied adolescents and their age, gender,

educational level, and duration of disease at a p-value <0.05.

Table 10 reflects that patients' age, gender (female), self-advocacy skills, and patients' ability to take care of their health were statistically significant independent positive predictors of transition readiness among the studied adolescents at p= <0.05. **Table 11** illustrated that talking with providers score; and managing medications score were statistically significant independent positive predictors of self-advocacy skills among the studied adolescents. The studied variables can determine 24% of self-advocacy skills.

Table (1): Characteristics of the Studied Adolescent Patients (n=105)

Variables		No	%
Age / years	12-<14	47	44.8
	14-<16	31	29.5
	16-18	27	25.7
Gender	Males	58	55.2
	Females	47	44.8
Educational status	Student	100	95.2
	Not student nor worker	5	4.8
Educational level	Preparatory	71	71
	Secondary	27	27
	University	2	2
Age of disease onset	Mean ±SD Median (range)	7.51±3.95 8(1-14)	
Duration of disease	1-<5 years	42	40.0
	5 -10 years	27	25.7
	>10 years	36	34.3
Classification of kidney disease	ESKD[a] CKD[b]	32 73	30.5 69.5
Medical diagnosis	CAKUT[c]	39	37.1
	Nephrotic Syndrome	27	25.7
	Glomerular diseases	36	34.3
	Anemia	3	2.9

a: End Stage Kidney Disease (ESKD)
b: Chronic Kidney Disease (CKD)
c: Congenital Anomalies of Kidney and Urinary Tract (CAKUT)

Table (2): Factors Related To Self-Advocacy and Self-Care Practices of the Studied Adolescent Patients (n=105)

Variables		No	%
Previous health education Have you received any health education about your illness before	Yes	65	61.9
	No	40	38.1
Source of information [d] If the answer was yes, what is the source of information?	Internet	11	10.5
	Physician	65	61.9
	Nurse	21	20.0
Have you participated in or created a support group for patients with the same disease?	Yes	24	22.9
	No	81	77.1
If the answer was yes, specify the type of your participation	Member	24	100.0
Do you consider yourself able to defend/advocate your rights as a patient?	Yes	52	49.5
	No	53	50.5
Do you consider yourself able to participate effectively in making health decisions related to your disease?	Yes	44	41.9
	No	61	58.1
Do you consider yourself capable of taking care of your health?	Yes	52	49.5
	No	53	50.5

d: More than one response

Table (3): Level of Self-Advocacy Skills of the Studied Adolescent Patients (n=105)

Self-advocacy skills		Level	No.	%
Illness Education		High	16	15.2
Mean ±SD	10.7±3.54	Moderate	29	27.6
Median(range)	10 (4-20)	Low	60	57.2
Assertiveness		High	17	16.2
Mean ±SD	10.22±3.26	Moderate	24	22.9
Median(range)	10 (4-20)	Low	64	61.0
Mindful Non-adherence		High	12	11.4
Mean ±SD	8.51±3.57	Moderate	16	15.2
Median(range)	8 (4-18)	Low	77	73.3
Total Self-advocacy		High	6	5.7
Mean ±SD	28.8±7.12	Moderate	28	26.7
Median(range)	28 (13-48)	Low	71	67.6

Table (4): The Level of Transition Readiness from Pediatric to Adult Healthcare of the Studied Adolescent Patients (n=105)

Transition Readiness		Level	No.	%
Managing Medications		High	31	29.5
Mean ±SD	12.89±5.49	Moderate	30	28.6
Median(range)	14(5-25)	Low	44	41.9
Keeping Appointments		High	38	36.2
Mean ±SD	10.78±5.62	Moderate	12	11.4
Median(range)	10(4-20)	Low	55	52.4
Tracking Health Issues		High	15	14.3
Mean ±SD	13.59±6.15	Moderate	25	23.8
Median(range)	13(6-30)	Low	65	61.9
Talking with Providers		High	33	31.4
Mean ±SD	12.8±6.51	Moderate	11	10.5
Median(range)	12(5-25)	Low	61	58.1
Readiness Level For The Transition From Pediatric To Adult Healthcare		High	20	19.0
Mean ±SD	50.06±19.15	Moderate	25	23.8
Median(range)	50 (20-93)	Low	60	57.2

Table (5): Beliefs of the Studied Adolescent Patients about Their Self-Care Abilities (n=105)

Beliefs		No.	%
How important is it to you to manage your own health care?	High	55	52.4
	Moderate	15	14.3
	Low	35	33.3
How confident do you feel about your ability to manage your own health care?	High	34	32.4
	Moderate	11	10.5
	Low	60	57.1

Table (6): Correlation between Transition Readiness and Self-Advocacy Skills of the Studied Adolescent Patients (n=105)

Variables	Transition readiness		Self-advocacy skills	
	r	P	r	P
Transition readiness	1	.		
Self-advocacy skills	.386	0.0001**	1	.
Illness education score	.434	0.0001**		
Assertiveness score	.424	0.0001**		
Mindful non-adherence score	-0.138	0.161		
Managing medications score			.430	0.0001**
Keeping appointments score			.206	0.035*
Tracking health issues score			0.127	0.197
Talking with providers score			.391	0.0001**
How important is it to you to manage your own health care?	.482	0.0001**	.237	0.015*
How confident do you feel about your ability to manage your own health care?	.495	0.0001**	.320	0.001**

Pearson' correlation coefficient (r) ** Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

Table (7): Relation Between Factors Related to Self-Advocacy skills and Self-care Practices of The Studied Adolescent Patients and Their Level of Self-Advocacy skills and Their Transition Readiness (N=105)

Variables	Self-Advocacy Level									Transition Readiness								
	High		Moderate		Low		n	χ^2	p	high		moderate		Low		N	χ^2	p
	No.	%	No.	%	No.	%				No.	%	No.	%	No.	%			
Previous health education																		
Yes	3	4.6	24	36.9	38	58.5	65	9.21	0.01*	11	16.9	18	27.7	36	55.4	65	1.58	0.46
No	3	7.5	4	10.0	33	82.5	40			9	22.5	7	17.5	24	60.0	40		
Have you participated in or created a support group for patients with the same disease?																		
Yes	2	8.3	7	29.2	15	62.5	24	0.57	0.75	5	20.8	7	29.2	12	50.0	24	0.71	0.7
No	4	4.9	21	25.9	56	69.1	81			15	18.5	18	22.2	48	59.3	81		
Do you consider yourself able to defend/advocate your rights as a patient?																		
Yes	1	1.9	20	38.5	31	59.6	52	8.94	0.01*	18	34.6	13	25.0	21	40.4	52	18.2	0.0001*
No	5	9.4	8	15.1	40	75.5	53			2	3.8	12	22.6	39	73.6	53		
Do you consider yourself able to participate effectively in making health decisions related to your disease?																		
Yes	1	2.3	17	38.6	26	59.1	44	6.45	0.04*	13	29.5	13	29.5	18	40.9	44	8.92	0.012*
No	5	8.2	11	18.0	45	73.8	61			7	11.5	12	19.7	42	68.9	61		
Do you consider yourself capable of taking care of your health?																		
Yes	0	.0	18	34.6	34	65.4	52	8.40	0.02*	15	28.8	13	25.0	24	46.2	52	7.43	0.024*
No	6	11.3	10	18.9	37	69.8	53			5	9.4	12	22.6	36	67.9	53		

χ^2:Chisquare test, P>0.05 no significant, P≤0.05: significant

Table (8): Relation between Characteristics of the Studied Adolescent Patients and Their Level of Self-Advocacy Skills (n=105)

Variables	Self-Advocacy Level						n	χ^2	P
	high		moderate		low				
	No.	%	No	%	No.	%			
Age / years									
12-<14	4	8.5	7	14.9	36	76.6	47	8.05	0.09
14-<16	2	6.5	10	32.3	19	61.3	31		
16-18	0	.0	11	40.7	16	59.3	27		
Gender									
Male	4	6.9	16	27.6	38	65.5	58	0.44	0.8
Female	2	4.3	12	25.5	33	70.2	47		
Educational status									
Student	6	6.0	25	25.0	69	69.0	100	3.08	0.21
Not student nor worker	0	.0	3	60.0	2	40.0	5		
Classification of Kidney Disease									
ESKD[a]	3	9.4	13	40.6	16	50.0	32	6.56	0.04*
CKD[b]	3	4.1	15	20.5	55	75.3	73		
Medical Diagnosis									
CAKUT[c]	1	2.6	17	43.6	21	53.8	39	17.52	0.008*
Nephrotic Syndrome	0	.0	4	14.8	23	85.2	27		
Glomerular diseases	4	11.1	7	19.4	25	69.4	36		
Anemia	1	33.3	0	.0	2	66.7	3		
Duration of Disease									
1-< 5 years	2	4.8	9	21.4	31	73.8	42	5.66	0.23
5 -10 years	0	.0	7	25.9	20	74.1	27		
>10 years	4	11.1	12	33.3	20	55.6	36		

χ^2:Chi square test, P>0.05 no significant, P<0.05: Significant

Table (9): Relation between Characteristics of the Studied Adolescent Patients and Their Transition Readiness from Pediatric to Adult Healthcare (n=105)

Variables	Transition Readiness						N	χ^2	p
	High		moderate		low				
	No.	%	No.	%	No.	%			
Age / years									
12-<14	0	.0	13	27.7	34	72.3	47	43.1	0.0001*
14-<16	4	12.9	11	35.5	16	51.6	31		
16-18	16	59.3	1	3.7	10	37.0	27		
Gender									
Male	8	13.8	10	17.2	40	69.0	58	7.39	0.03*
Female	12	25.5	15	31.9	20	42.6	47		
Educational status									
Student	17	17.0	25	25.0	58	58.0	100	6.14	0.051
Not student nor worker	3	60.0	0	.0	2	40.0	5		
Educational level									
Preparatory	5	7.0	21	29.6	45	63.4	71	17.55	0.0001*
Secondary	12	41.4	4	13.8	13	44.8	29		
Classification of Kidney Disease									
ESKD[a]	9	28.1	8	25.0	15	46.9	32	2.87	0.24
CKD[b]	11	15.1	17	23.3	45	61.6	73		
Medical diagnosis									
CAKUT[c]	11	28.2	6	15.4	22	56.4	39	6.64	0.36
Nephrotic Syndrome	4	14.8	6	22.2	17	63.0	27		
Glomerular diseases	4	11.1	12	33.3	20	55.6	36		
Anemia	1	33.3	1	33.3	1	33.3	3		

Duration of disease									
1-< 5 years	1	2.4	16	38.1	25	59.5	42	34.24	0.0001*
5 -10 years	2	7.4	8	29.6	17	63.0	27		
>10 years	17	47.2	1	2.8	18	50.0	36		

χ^2:Chisquare test, p>0.05 no significant, p<0.05: Significant

Table (10): Multiple Linear Regression Model for Predictors of Transition Readiness among the Studied Adolescent Patients (n=105)

Predictors	**Unstandardized Coefficients**	**T**	**Sig.**
	B		
(Constant)	20.6		
Age per years	3.452	3.218	.002
Gender(female)	8.765	2.828	.006
Self-Advocacy Skills	.779	3.788	.0001
Patients capable of taking care of their health	9.714	2.656	.009
Model	r= 0.68 R^2 =0.46 F =10.5 P=0.0001*		

β = regression coefficients, SE: standard error, $R^{2:}$ R square, f test *significant P<0.05

Table (11): Multiple Linear Regression Model for Predictors of Self-Advocacy Skills among the Studied Adolescent Patients (n=105)

Predictors	**Unstandardized Coefficients**	**T**	**Sig.**
	B		
(Constant)	21.6		
Talking with providers score	.339	2.169	.033
Managing medications score	.495	3.570	.001
Model	r= 0.49 R^2 =0.24 F =5.06 P=0.0001*		

β = regression coefficients, SE: standard error, $R^{2:}$ R square , f test *significant P<0.05

Discussion

Self-advocacy is the process by which patients take an active role in their own health and medical care. It involves understanding one's own health needs, communicating those needs clearly to healthcare providers, and making informed decisions about treatment options. This includes asking questions, seeking second opinions, understanding the risks and benefits of different treatments, and ensuring that personal values and preferences are respected in the decision-making process. Self-advocacy empowers patients to take control of their health and work collaboratively with healthcare professionals to achieve the best possible outcomes (Eaton, 2024; Hagan et al., 2018).

More than two-thirds of adolescents with chronic and end-stage kidney diseases in the current study had low total self-advocacy skills (were not able to advocate themselves in the

health care system). Similar low self-advocacy scores were reported at baseline assessment of adolescents with chronic illness (Mackie et al., 2018). To advocate themselves adolescents with CKD and ESKD should have the ability to recognize their needs, identify the type of support that could be beneficial, and express these needs to others. Individual factors such as insufficient knowledge about their health conditions, treatment options, or how the healthcare system works may affect adolescents' ability to advocate for themselves effectively.

Parents and healthcare providers may not adequately teach self-advocacy skills, leaving adolescents unprepared to manage their healthcare needs independently. Moreover, adolescents are still developing cognitive and emotional maturity. They may lack the confidence, decision-making skills, or emotional resilience needed to advocate for themselves in complex healthcare environments.

Adolescents may also, rely heavily on parents or guardians to manage their healthcare, reducing their opportunities to develop self-advocacy skills. Parents who are overly involved in their child's healthcare may unintentionally prevent them from developing self-advocacy skills. Adolescents who are not allowed to make decisions or speak up during medical appointments may not learn how to do so on their own. Other factors that could also contribute to the low self-advocacy skills of the studied adolescents include social and cultural influences, such as norms discouraging questioning authority figures (physicians), intimidating healthcare environments, communication barriers, and low self-esteem.

Some of the previously mentioned factors were mirrored in the results of the current study. As statistically significant relations were found between levels of self-advocacy skills of the studied adolescents and receiving any health education about the illness, the ability to defend/advocate their rights as a patient and take care of their health, as well as adolescents' ability to participate effectively in making health decisions related to their disease.

The results revealed that nearly two-fifths of the studied adolescents did not receive any health education about their illness before and more than half of them reported their inability to defend/advocate their rights as a patient or take care of their health. Moreover, three-fifths of the studied adolescents were not able to participate effectively in making health decisions related to their disease. Huang et al., (2023) go in line with the findings of the present study and reported a positive effect of two educational interventions in improving some aspects of adolescents' self-advocacy including; illness education, and assertiveness. This reflects the role of health education as an important factor affecting self-advocacy.

Regarding readiness for transition, it was found that nearly three-fifths of the studied adolescents with chronic and end-stage kidney diseases had low readiness for transition to adult health care. In Alignment with these findings, Abdwani et al., (2022) reported that the majority of chronically ill studied adolescents had low transition readiness scores. Also, low readiness for transition baseline scores were reported among chronically ill adolescents (Mackie et al., 2018). Jensen et al., (2017) support existing evidence that adolescents and young adults often lack adequate preparation for transition. Different results were found by Sawicki et al., (2014), where both the studied adolescents and their

parents reported moderate readiness for transition to adult care.

Several factors contribute to low readiness for transition to adult health care among adolescents with chronic and end-stage kidney diseases. These include a lack of self-management skills, insufficient health education, dependency on parents or caregivers, and emotional and psychological difficulties. Additionally, inadequate support systems, poor transition planning, social and developmental challenges, the complexity of the disease, and differences between pediatric and adult care systems can further hinder readiness.

The transition from pediatric to adult health care services, known as health care transition (HCT), is a process that demands thorough preparation. For adolescents and young adults with chronic or end-stage renal disease (ESRD), this transition can be lengthy due to various physical, psychological, familial, or environmental factors (Díaz-González de Ferris et al., 2017). Additional factors that make health care transition difficult for many adolescents include; cognitive development, lack of social support, heightened behavioral risks typical of adolescents, poor coordination between pediatric and adult healthcare systems, and gaps in health insurance during the transition period (Reiss & Gibson, 2002; Reiss et al., 2005; Scal & Ireland, 2005).

Highly statistically significant correlations were found between transition readiness and the studied adolescents' self-care beliefs about the importance of managing health and confidence in their abilities to manage their health. Although more than half of the studied adolescents believe that it is highly important to manage their healthcare issues, nearly three-fifths of them had low confidence in their abilities to manage their healthcare.

The reported low confidence in the studied adolescent abilities to manage their health was reflected by low reported readiness to manage many specific tasks required for transition including; managing medications, keeping appointments, tracking health issues, and talking with providers and contradicted their beliefs about the importance of independent management of their health. This discrepancy between self-care beliefs and transition readiness skills is consistent with the findings of another survey that assesses care transition readiness among adolescents and young adults and found a similar disparity between high beliefs in self-care and low transition readiness (Sawicki et al., 2014).

Statistically significant relationships were found between the transition readiness of the studied adolescents and their age, gender, educational level, and duration of the disease. Moreover, age, gender (female), self-advocacy skills, and adolescents' ability to take care of their health were positive predictors for transition readiness among the studied adolescents with CKD and ESKD. Evidence proved that transition readiness is affected by various modifiable factors such as psychosocial aspects and self-management/transition education, as well as non-modifiable factors like demographic, ecological, and disease-related aspects (Varty & Popejoy, 2020).

In agreement with these findings, other studies reported that a higher overall transition readiness score was associated with age (being older) (Stewart et al., 2017; Haarbauer-Krupa et al., 2019; Abdwani et al., 2022), and being female (Gray et al., 2015;

Javalkar et al., 2016; Eaton et al., 2017; Hart et al., 2017; Lazaroff et al., 2019; Allemang et al., 2022). On the contrary, Gumidyala et al. (2018) and Dwyer-Matzky et al. (2018) did not find a relationship between gender and transition readiness.

As regards the relationship between transition readiness skills and duration of the disease, Fenton et al., (2015) did not agree with the results of the present study and concluded that disease-related factors are less important in predicting transition readiness among adolescents with chronic kidney diseases. Whitfield et al., (2015); Carlsen et al., (2017) also did not find any relationship between disease duration and readiness for transition. Contrary to the results of the present study Bingham et al. (2015); Treadwell et al., (2016) did not find any association between adolescents' educational level and transition readiness.

The findings of the present study revealed a highly statistically significant positive correlation between total transition readiness and total self-advocacy skills. Moreover, transition readiness was positively correlated with specific aspects of self-advocacy as illness education and assertiveness. On the same hand, self-advocacy skills were positively correlated with discrete tasks necessary for transition as managing medications, keeping appointments, and talking with providers. These findings can be attributed to the fact that self-advocacy skills and readiness for care transition are closely related among adolescents with chronic diseases. As self-advocacy involves the ability of individuals to understand their condition, communicate their needs, make informed decisions, and take responsibility for their care (Chambers, 2024). These skills are essential for successfully navigating the transition from pediatric to adult-focused healthcare services.

The relationship between self-advocacy and transition readiness varies, but generally, strong self-advocacy empowers adolescents by boosting their confidence to manage their health care and transition smoothly. It fosters independence, improves communication with healthcare providers, enhances self-management of chronic diseases (Hagan et al., 2017), and helps adolescents adjust better to the emotional and social challenges of adult care.

Even though Stewart et al. (2017) contradicted the assumption that high self-advocacy skills are associated with improved self-management skills and better transition readiness and reported a gap between the studied adolescents' ability to advocate for themselves and their ability to take on the responsibilities of managing their chronic illness independently. Overall, self-advocacy is fundamental in equipping adolescents with chronic diseases for a successful transition to adult care, ensuring long-term health and well-being.

Conclusion

Adolescents with chronic and end-stage kidney diseases generally exhibit low self-advocacy skills and low readiness for transition from pediatric to adult healthcare. Moreover, a highly statistically significant correlation was found between self-advocacy and transition readiness among the studied adolescents. This strong positive correlation suggests that improving self-advocacy skills could be key to enhancing readiness for transition.

Recommendations

Implementing targeted interventions to improve self-advocacy skills in

adolescents with CKD and ESKD is crucial. This includes educational programs, counseling, and training to help them better understand their condition, communicate with healthcare providers, and take responsibility for their care. Enhancing these skills is expected to increase their readiness for transitioning to adult healthcare, leading to better health outcomes. There is also an urgent need for implementing comprehensive transition programs with structured transition planning, transition education, support, family involvement, and regular assessments to evaluate readiness and adjust the plan as needed.

Further longitudinal studies should be conducted to track the development of self-advocacy skills and transition readiness over time. Also, further qualitative studies are needed to gain deeper insights into specific barriers that adolescents with chronic and end-stage kidney diseases face in developing self-advocacy skills.

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